

# CAHPS Child Survey: Questions for Children with Chronic Conditions

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## Introduction

To better address the needs of children with chronic conditions (commonly referred to as children with special health care needs), the CAHPS Consortium decided in 2002 to integrate a new set of items into the CAHPS health plan questionnaires for children. The expanded Child Survey allows sponsors to:

- Identify children who have chronic conditions;
- Assess their experience with the health care system; and
- Compare it to the experiences of similar children in other health plans and/or children without chronic conditions in the same plan.

This document explains the why this information is useful, what is included in this set of items, and how sponsors and other organizations can use the survey results.

## How Does CAHPS Define Children with Chronic Conditions?

The CAHPS methodology uses the Maternal and Child Health Bureau's definition of children with special health care needs, which is based on consequences rather than specific conditions or diseases:

“Children with special health care needs are those who have a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that generally required by children.”<sup>1</sup>

Research indicates that children with chronic conditions account for 15 to 18 percent of all children under 18, although some sponsors of CAHPS may serve a relatively higher proportion of children with chronic conditions than is found in the general population.<sup>2</sup>

## Why Is This Information Important?

While the numbers of children with chronic conditions may be small, several factors point to the need to measure and report on quality of care for this segment of the population:

- **Financial impact.** Children with chronic conditions consume a preponderance of the health care dollars spent on children, with estimates ranging from 80 to 90 percent.<sup>3</sup>
- **Evidence of poor quality.** Researchers have found that quality of care for children with chronic conditions is often inadequate. According to studies conducted by FACCT-The Foundation for Accountability, parents of children with chronic conditions rate their experiences with care at a level

<sup>1</sup> McPherson M, Arango P, Fox H, et al. (1998). A new definition of children with special health care needs. *Pediatrics*, 102, 137-40.

<sup>2</sup> Newacheck PW, Strickland B, Shonkoff JP, et al. (1998). An epidemiologic profile of children with special health care needs. *Pediatrics*, 102(1 Pt 1), 117-23. Stein RE and Silver EJ. (1999). Operationalizing a conceptually based noncategorical definition: A first look at U.S. children with chronic conditions. *Arch Pediatr Adolesc Med*, 153(1), p. 68-74.

<sup>3</sup> See Lewit EM and Monheit AC. (1992). Expenditures on health care for children and pregnant women. *Future of Children*, 2, 95-114 (David and Lucile Packard Foundation).



that ranges from 50 percent to 80 percent of what would be considered optimal.<sup>4</sup>

It is critical to assess and track quality of care for this vulnerable segment so that parents, health plans, and other survey sponsors can evaluate how well the needs of children with chronic conditions are being met and identify which aspects of care need to be improved.

- **Equity.** The experiences that children with chronic conditions have with health plans and providers are often different from those of healthy children, who primarily rely on the health care system for preventative and acute care. Families, health plans, and policymakers need to know if quality of care is not consistent for all children and which plans are best suited to meet the needs of children with chronic conditions.
- **The need for relevant information.** The continual needs of children with chronic conditions far exceed those of their peers, particularly with respect to the type, scope, and frequency of health care services they require. They also have a greater demand for health information, education, partnership with providers, and coordination of care. When reviewing their coverage options, the parents of these children need access to comparative performance information that is relevant to their circumstances.

## Contents of the Children's Chronic Conditions Set

The chronic condition set for children consists of:

- A set of 31 **supplemental questions** regarding the health care experiences of children with chronic conditions; and
- A five-item **screeners** that classifies children with chronic conditions during the analysis stage after the survey has been administered.

## What Are the Supplemental Questions?

The 31 supplemental questions in the instruments for children focus on topics with special relevance to children with chronic conditions. These topics are reflected in the following composite measures:

- Access to prescription medicines;
- Access to specialized services;
- Family-centered care:
  - Having a personal doctor or nurse who knows the child;
  - Shared decisionmaking;
  - Getting needed information; and

<sup>4</sup> Bethell, C., Lansky, D., and Hendryx, M. (2000, September). The Robert Wood Johnson Foundation National Strategic Indicators Survey: RWJF Priority and Program Area Performance Indicators Summary Report. Portland, OR: FACCT-The Foundation for Accountability. Bethell, C. (2000, July). *Measuring patient centered care across consumer relevant domains of quality: A report prepared for the Institute of Medicine Committee on the National Quality Report on Health Care.*



- Coordination of care and services.

The response sets for these supplemental questions are consistent with the core items in the questionnaire.

### **What Are the Screener Items?**

The five-item screener is a tool used during the analysis of the data to determine which responses to the CAHPS Child Survey reflect the experiences of children with chronic conditions.

### ***The Problem: Children with Chronic Conditions Are Hard to Find***

To identify children with special health needs, it is not sufficient to look for categories of children, i.e., those with specific conditions or diseases:

- First, the prevalence of any given chronic condition among children is relatively low.
- Second, there are a large number of applicable diagnoses, many of which are very rare.
- Third, identification strategies that rely on diagnoses have been known to miss children who should qualify as having chronic conditions. Reasons for this problem include coding errors, misdiagnoses, lack of access to care, and the global or developmental nature of some childhood problems.
- Finally, there are many definitions of children with chronic conditions (or special health care needs), and each results in a different set of conditions and/or codes to operationalize the definition.

### ***Our Approach: Focus on Consequences***

The CAHPS methodology addresses this problem by classifying children as having a chronic condition if they report one or more of the consequences associated with such conditions.

### ***Screener Criteria***

The screener is designed to identify children who meet three criteria:

- Criteria #1: The child currently experiences a specific consequence.
- Criteria #2: The consequence results from a medical, behavioral, or other health condition.
- Criteria #3: The duration or expected duration of the condition is at least 12 months.

### ***What Does the Screener Ask?***

The screener consists of five main questions, each of which has three parts. The questions cover the following five health consequences:

- Use or need of prescription medication;



- Above average use or need of medical, mental health, or education services;
- Function limitations compared with others of the same age;
- Use or need of specialized therapies (e.g., occupational therapy, physical therapy, speech); and
- Treatment or counseling for emotional, behavioral, or developmental problems.

If the answer to the first part of the question is "yes," the respondent moves on to the second part to say whether the consequence is due to any kind of health condition. If so, the respondent continues to the third part, which asks whether the condition has lasted or is expected to last for at least 12 months. (The one exception to this pattern is the last screener question, which has only two parts.)

A child who meets all three criteria for one or more of the five main questions would qualify as having a chronic condition. On average, 16 to 20 percent of the general population of children meets these criteria. When you analyze the data, the number of children who meet the screener criteria will be the denominator for calculations of quality measures for children with chronic conditions.

### Can I Add Other Items?

Sponsors of the CAHPS Child Survey still have the option of adding other supplemental question from the CAHPS Health Plan Survey (not related to chronic conditions) as well as their own questions.

Any additional questions contribute to the time required of respondents. However, while a lengthy survey drops the response rate for most survey populations, this does not hold true for the population of children with chronic conditions.

### For More Information

- To see the sampling guidelines regarding the minimum number of responses required for reporting purposes, please see *Fielding the CAHPS Health Plan Survey: Medicaid Version* [Doc. No. 13a] in the **CAHPS Health Plan Survey and Reporting Kit**.
- If you are interested in using the screener on its own to identify children with chronic conditions, please contact the Child and Adolescent Health Measurement Initiative (CAHMI) at <http://dch.ohsuhealth.com/index.cfm?pageid=451&sectionID=133&open=148>).

## Gathering, Analyzing, and Reporting the Data

Sponsors of the CAHPS Child Survey should consider the full range of opportunities and challenges in the process of gathering, analyzing and reporting their data. Below are some factors to bear in mind for those interested in conducting this survey.



## Fielding the Survey

Since less than one-fifth of all children have chronic conditions, you have to make a special effort to ensure that you obtain a sufficient number of responses from that segment to report statistically valid results.

To maximize the number of usable responses, you can follow the sampling protocol explained in *Fielding the CAHPS Health Plan Survey: Medicaid Version* [Doc. No. 13a] in the **CAHPS Health Plan Survey and Reporting Kit**.

## Analyzing the Data

If you obtain a sufficient number of responses, you can analyze the data for children identified as having chronic conditions separately from the data for the general population of children. For guidance in conducting this analysis, please contact the CAHPS User Network by email ([cahps1@ahrq.gov](mailto:cahps1@ahrq.gov)) or by telephone: (800) 492-9261.

## Reporting the Data

With the data you collect from the Child Survey, you can provide parents, providers, health plans, and purchasers with useful information about the care provided to an important segment of the child population. Parents and caregivers can incorporate the composite measures into their health care coverage decisions. Other potential audiences for the reports include accrediting agencies, state Medicaid agencies, SCHIP programs, children's advocacy groups, and Federal agencies.

You can use the information in two ways:

- Report the standard CAHPS composites (getting needed care, getting care quickly, etc.) for two separate groups:
  - The general population of children
  - The children with chronic conditions

This will allow you to identify the ways in which the experiences and perceptions of these two groups differ as well as the ways in which they are consistent.

- Report only the composites for children with chronic conditions:
  - Access to prescription medicines
  - Access to specialized services
  - Family-centered care
  - Coordination of care and services

These composites are designed to capture the four domains of care that are especially important for this segment of the population.

For help in reporting the composites resulting from this analysis, see the guidelines in the Reporting Resources section of the CAHPS Web site. You may also contact the CAHPS User Network at [cahps1@ahrq.gov](mailto:cahps1@ahrq.gov) for further assistance.



### What If I Do Not Want Results for Children with Chronic Conditions?

If you are only interested in gathering and reporting basic information on the health care of children age 17 and under (i.e., no information on the specific experiences of those with chronic conditions), you may omit the chronic conditions set from the questionnaire. You will be left with only the core items of the child questionnaire, with or without other supplemental questions.

- **Finding the items.** The chronic condition items are highlighted in yellow for easy identification and removal.
- **Reviewing remaining items.** After you delete the chronic condition items, please check the questionnaire carefully to make sure that the remaining items are numbered correctly.

### Developers of the Children's Chronic Condition Set

The chronic condition set for children was developed through the Child and Adolescent Health Measurement Initiative (CAHMI), with substantial input from the CAHPS research team and the Agency for Healthcare Research and Quality (AHRQ).

#### What is CAHMI?

Primarily funded by the David and Lucile Packard Foundation and The Commonwealth Fund, the CAHMI is a national collaboration of more than 80 organizations. First established by FACCT-The Foundation for Accountability and the National Committee for Quality Assurance (NCQA), it is now housed at Oregon Health & Science University in the Department of Pediatrics.

CAHMI receives guidance from four national advisory committees comprised of consumers, researchers, providers, policymakers, and other stakeholders. The Living with Illness Task Force advised the CAHMI research staff during the development, testing, and refinement of the children's chronic conditions set.

#### For More Information

See CAHMI's Web site at

<http://dch.ohsuhealth.com/index.cfm?pageid=451&sectionID=133&open=148>.

#### Related Resources

- The Child Health Tool Box – [www.ahrq.gov/chtoolbx](http://www.ahrq.gov/chtoolbx)
- The Foundation for Accountability (FACCT) – <http://www.markle.org/resources/facct/index.php>
- National Committee for Quality Assurance (NCQA) – [www.ncqa.org](http://www.ncqa.org)



## Appendix:

### Items in the Reporting Composites for Children

Sponsors of the Health Plan Survey can report five composites for children:

- Getting needed care for a child
- Getting care quickly for a child
- How well the child's doctors communicate
- Courtesy, respect, and helpfulness of office staff
- Health plan customer service, information, and paperwork

**Important Note:** The Child questionnaires also include a set of items for children with chronic conditions. These composites are listed after the core composites.

#### Getting Needed Care for a Child

Q7	Since you joined your health plan, how much of a problem, if any, was it to get a personal doctor or nurse you are happy with?	<b>Response Format</b> <ul style="list-style-type: none"> <li>• A big problem</li> <li>• A small problem</li> <li>• Not a problem</li> </ul>
Q13	In the last 12 months, how much of a problem, if any, was it to see to a specialist that your child needed to see?	
Q26	In the last 12 months, how much of a problem, if any, was it to get the care, tests, or treatments you or a doctor believed necessary?	
Q28	In the last 12 months, how much of a problem, if any, were delays in health care while you waited for approval from your child's health plan?	

#### Getting Care Quickly for a Child

Q18	In the last 12 months, when you called during regular office hours, how often did you get the help or advice you needed for your child?	<b>Response Format</b> <ul style="list-style-type: none"> <li>• Never</li> <li>• Sometimes</li> <li>• Usually</li> <li>• Always</li> </ul>
Q20	In the last 12 months, when your child needed care right away for an illness, injury, or condition, how often did your child get care as soon as you wanted?	
Q22	In the last 12 months, not counting times you needed health care right away, how often did your child get an appointment for health care as soon as you wanted?	
Q29	In the last 12 months, how often was your child taken to the exam room within 15 minutes of his or her appointment?	



### How Well the Child's Doctors Communicate

Q32	In the last 12 months, how often did your child's doctors or other health providers listen carefully to you?	<b>Response Format</b> <ul style="list-style-type: none"> <li>• Never</li> <li>• Sometimes</li> <li>• Usually</li> <li>• Always</li> </ul>
Q33	In the last 12 months, how often did your child's doctors or other health providers explain things in a way you could understand?	
Q34	In the last 12 months, how often did your child's doctors or other health providers show respect for what you had to say?	
Q36	In the last 12 months, how often did doctors or other health providers explain things in a way your child could understand?	

### Courtesy, Respect, and Helpfulness of Office Staff

Q30	In the last 12 months, how often did office staff at your child's doctor's office or clinic treat you and your child with courtesy and respect?	<b>Response Format</b> <ul style="list-style-type: none"> <li>• Never</li> <li>• Sometimes</li> <li>• Usually</li> <li>• Always</li> </ul>
Q31	In the last 12 months, how often were office staff at your child's doctor's office or clinic as helpful as you thought they should be?	

### Health Plan Customer Service, Information, and Paperwork

Q63	In the last 12 months, how much of a problem, if any, was it to find or understand this information (in written material or on the Internet)?	<b>Response Format</b> <ul style="list-style-type: none"> <li>• A big problem</li> <li>• A small problem</li> <li>• Not a problem</li> </ul>
Q65	In the last 12 months, how much of a problem, if any, was it to get the help you needed when you called your child's health plan's customer service?	
Q67	In the last 12 months, how much of a problem, if any, did you have with paperwork for your child's health plan?	

**Note:** The question numbers refer to items in the CAHPS Child Commercial Questionnaire 3.0. To identify corresponding questions on different questionnaires, see the crosswalk table in the document called *Preparing a Questionnaire Using the CAHPS Health Plan Survey 3.0* [see Table 2-2 in doc 12], which is part of the Health Plan Survey and Reporting Kit. These two tables allow you to develop equivalent composites for any of the CAHPS Health Plan questionnaires for children. This document also lists the topics covered by the supplemental items.



## Items in the Composites for Children with Chronic Conditions

Sponsors can report four composites for children with chronic conditions:

- Parents' experiences with prescription medicine
- Parents' experiences getting specialized services for their child
- Family-centered care
- Parents' experiences with coordination of their child's care

### Parents' Experiences with Prescription Medicine

Q70	In the last 12 months, how much of a problem, if any, was it to get your child's prescription medicine?	<b>Response Format</b> <ul style="list-style-type: none"> <li>• A big problem</li> <li>• A small problem</li> <li>• Not a problem</li> </ul>
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### Parents' Experiences Getting Specialized Services for Their Child

Q52	In the last 12 months, how much of a problem, if any, was it to get special medical equipment for your child?	<b>Response Format</b> <ul style="list-style-type: none"> <li>• A big problem</li> <li>• A small problem</li> <li>• Not a problem</li> </ul>
Q55	In the last 12 months, how much of a problem, if any, was it to get special therapy for your child (physical, occupational, or speech)?	
Q58	In the last 12 months, how much of a problem, if any, was it to get this treatment or counseling for your child (for an emotional, developmental, or behavioral problem)?	

### Family-Centered Care

This composite combines three topics:

- Parents' experiences with the child's personal doctor or nurse
- Parents' experiences with shared decisionmaking
- Parents' experiences with getting needed information about their child's care

### Parents' Experiences with the Child's Personal Doctor or Nurse

Q8	In the last 12 months, did your child's personal doctor or nurse talk with you about how your child is feeling, growing, or behaving?	<b>Response Format</b> <ul style="list-style-type: none"> <li>• Yes</li> <li>• No</li> </ul>
Q10	Does your child's personal doctor or nurse understand how these medical, behavioral, or other health conditions affect your child's day-to-day life?	
Q11	Does your child's personal doctor or nurse understand how your child's medical, behavioral or other health conditions affect your family's day-to-day life?	



### Parents' Experiences with Shared Decisionmaking

Q43	When decisions were made in the last 12 months, how often did your child's doctors or other health providers offer you choices about your child's health care?	<b>Response Format</b> <ul style="list-style-type: none"> <li>• Never</li> <li>• Sometimes</li> <li>• Usually</li> <li>• Always</li> </ul>
Q44	When decisions were made in the last 12 months, how often did your child's doctors or other health providers discuss with you the good and bad things about each of the different choices you were given?	
Q45	When decisions were made in the last 12 months, how often did your child's doctors or other health providers ask you to tell them what choices you prefer?	
Q46	When decisions were made in the last 12 months, how often did your child's doctors or other health providers involve you as much as you wanted?	

### Parents' Experiences with Getting Needed Information About Their Child's Care

Q39	In the last 12 months, how often did your child's doctors or other health providers make it easy for you to discuss your questions or concerns?	<b>Response Format</b> <ul style="list-style-type: none"> <li>• Never</li> <li>• Sometimes</li> <li>• Usually</li> <li>• Always</li> </ul>
Q40	In the last 12 months, how often did you get the specific information you needed from your child's doctors and other health providers?	
Q41	In the last 12 months, how often did you have your questions answered by your child's doctors or other health providers?	

### Parents' Experiences with Coordination of Their Child's Care

Q50	In the last 12 months, did you get the help you needed from your child's doctors or other health providers in contacting your child's school or daycare?	<b>Response Format</b> <ul style="list-style-type: none"> <li>• Yes</li> <li>• No</li> </ul>
Q61	In the last 12 months, did anyone from your child's health plan, doctor's office or clinic help coordinate your child's care among these different providers or services?	

**Note:** The question numbers refer to items in the CAHPS Child Commercial Questionnaire 3.0. To identify corresponding questions on different questionnaires, see the crosswalk table in the document called *Preparing a Questionnaire Using the CAHPS Health Plan Survey 3.0* [see Table 2-2 in doc 12], which is part of the Health Plan Survey and Reporting Kit. These two tables allow you to develop equivalent composites for any of the CAHPS Health Plan questionnaires for children. This document also lists the topics covered by the supplemental items.